EUCERD JOINT ACTION WORKSHOP
GUIDING PRINCIPLES FOR SOCIAL CARE FOR PEOPLE LIVING WITH RARE DISEASES

State of the Art of social care pathways in France

Christel Nourissier
EURORDIS EUROPLAN Advisor

Patients's needs and expectations

- **inclusive and continuous life trajectories :**
  - **Early diagnosis and/or comprehensive evaluation of their complex needs by well trained, open and understanding professionals**
  - **Individual and regularly updated life plans according to their needs and wishes : inclusion in mainstream schools, or specialised schools , university and employment, with adapted support, day care or full time institutional care, if adapted.**
  - **Special attention to transition periods to prevent breakdowns: first schooling, teen age years, beginning of adult life, ageing**

- **Simplified paperwork, coordinated answers to their needs**

Social care provision in France

5,5 million people declare a limitation of activity linked to a disability

2005 : law on equality of rights and opportunities for people living with disabilities

- Creation of **CNSA, National Solidarity Fund for Autonomy**
  - Missions: fund social support and services, guarantee equal treatment in the whole territory, expertise, information and coordination of services
  - Budget: 16 billion euros, funded by social contributions of employers and workers, and taxes

- Creation of **100 MDPH « Maisons départementales* des Personnes Handicapées » : unique service at local level**.
  - Missions: information, evaluation, decisions, follow-up
- At patient’s and family’s request, MDPH coordinates evaluations of the loss of autonomy, then take all compensation decisions : allowances, education and employment, day care and full time care in homes for people with severe disabilities.
- « département »= county

Patients and families care pathways, ideally

✖ **= often lack of training and /or coordination**

Pediatrician
GP

Diagnosis of disease
Hospital
Centre of expertise:
Centre of reference or competence

Evaluation of capacities and disabilities
Centres of reference and competence, Resource centre OK
Specialised local centre with pluridisciplinary team OK?
local paramedical professionals, school MD ✖
MDPH social workers :

MDPH : individual plans ✖

Financial compensations

Supporting services at school
Specialised schools

Adapted employment

Home care

Day care services

Full time institutional care

Disability level and disability cards

How do patients get information on social policies/benefits/services

- on internet : orphanet, associations websites, CNSA and MDPH websites ; 2011 survey hotline Maladies Rares Info Service: 97%
- At the MDPH
- When calling Maladies Rares Info Service :14,4% calls in 2013
- Through patients associations
- In many centres of expertise
- In the townhalls social centres
- By chance…

The MDPH refers the patients to the different social structures

- Maps and directories of social services are published and available online at local level. They indicate if services are adapted to people with mental, sensory or motor deficiencies, more or less severe, but not to specific rare diseases, except very few cases.
- People with rare diseases and complex needs very often end up at the bottom of waiting lists
- Social services are mostly funded by taxes, also by the associations who run them. Services are free for the users.

Patients and families care pathways : the real life of people with disabilities

- After diagnosis, patients or families must send their applications to the MDPH themselves; most are reluctant to enter the system, not aware about the resources and benefits, and do not know how the system works : the associations play an important role.
- Lots of complex paperwork each year : the more severe their disabilities and isolation, the more discouraged they become.
- Gathering comprehensive medical and paramedical evaluations: a real time consuming challenge for families who can afford it :
  - Lack of coordination between MDs except in CoE,
  - up to 18 month delays for an appointment in some resource centres (ex: dysphasias, autistic spectrum disorders) and some reference centres.
- Many families give up.

Patients and families care pathways : specific challenges of evaluation

- Getting a comprehensive evaluation is very difficult
  - Medical certificate by local GPs or pediatricians often useless
  - All social workers in the MDPH use a common guideline, the GEVA, based on the ICF, more adapted to motor limitations of activities than mental or behavioural disabilities,

- Legal framework exclude many rare diseases
  - GEVA not adapted for many rare diseases ex: Ondine syndrome, xeroderma pigmentosum, Prader Willi syndrome, Smith Magenis syndrome, most autistic spectrum diseases...Human assistance funded only for people physically unable to perform « essential daily acts » mobility, communication, personal care, relationship with others. Max 3 hours surveillance a day if « active » (not passive).
  - GEVA not adapted for complex associations of disabilities 1+1 = 3 or 4!
  - Complementary tools have been developed to better evaluate psychic, mental disabilities, specific diseases, but they are sparingly used.

Patients and families care pathways the real life in the MDPH

- MDPH dilemma on complex cases : take an unadapted decision or ask for more evaluations?
- On average, 81% of cases are evaluated on files, 8% at the MDPH, 6% by telephone, only 5% at home.
- Long delays before decisions : by law, max 4 months, today, on average, 3 months for children and 4,4 months for adults! because of work overload : on average 24 people out of 1000 have asked MDPH for some kind of support in 2013.
- Much longer delays if the MDPH asks for more evaluations or if families or patients appeal to decisions taken.

Links between different departments/ care providers : unsatisfactory

- Link between medical and social care: medical certificate often not understandable, saying nothing about limitations of activities
- Link between social services: unsatisfactory. Services build walls instead of networks. Patients become « prisoners » of the service and dare not complain because there is no alternative or there are long waiting lists in other services; if the team breaks down, they are sent back home or to emergency clinics or psychiatric hospital (particularly if behaviour problems or evolutive disease). Then the MDPH are asked to redispatch them, much too late.

- Survey Maladies Rares Info Service 2013 : 48% patients are not satisfied with the coordination of social professionals…

Respite care,
personal assistants, day care centres

All do exist, but access is difficult. Just like all other services, they are not adapted to specific needs:

- evaluation of needs by the MDPH very limited and restricted for personal assistants
- Long waiting lists and few day care centres
- training and adaptation to the specific needs of people living with rare diseases necessary for personal assistants, day care and respite care as well as adapted housing
- Lack of coordination with other social services, in particular specialised schools

Measures on access to social policies and social services in 1st National Plan

- 1st National Plan for rare diseases 2005-2008: 131 National centres of reference designated in University hospitals (2005-2007), then 500 centres of competence in regional hospitals organised in disease specific networks linked to the centres of expertise (2007-2008)
- Missions of the centres of expertise :
  - Improve diagnosis, organise pluridisciplinary care from birth to end of life
  - Expertise and second opinion
  - Research, epidemiological surveillance and clinical trials
  - Production of National protocols for diagnosis and care, participation in European guidelines if possible
  - **Information and training of health and social professionals, patients and their family,**
  - **Coordination with provision of primary care, medical and social care**

Two pilot networks in the field of social services were launched by centres of expertises in the regions of Pays de la Loire and Languedoc Roussillon,

Measures on access to social policies and social services in 2nd National Plan

- Improve access to diagnostic and care: identification of 23 reference networks: *done* ; good practice guidelines networks/MDPH, support development of telemedecine : *to do*.
- Better link medical and social services:
  - develop complex case managers, *ongoing*
  - improve knowledge about consequences of diseases: limitation of activities, schooling problems, quality of life : **Orphanet disability project,** *ongoing*
  - Develop respite care for patients and their carers, prevention of carer's burn out and support : *to do*
- Improve health professional's practices: *to do*
  - Evaluate the contribution of new jobs, such as genetic counsellors, complex case managers…
  - Use permanent training
  - Create good practice guidelines for emergency situations
  - Promote on line training
- Disseminate information to patients and GPs : *to do*

Rare diseases and rare disabilities

- All rare diseases are not always associated to rare disabilities : some people living with RD can find the support they need in existing social services.
- However many do not. 65 % of rare diseases are associated with multiple disabilities.
- People with complex dependency needs require pluridisciplinary evaluations, collaboration of different local services, national centres of expertise and existing ressource centres.

Linking the 2nd National Plan to the National Strategy for rare disabilities

- 2009_2013 : a 1st National strategy for rare disabilities was funded by the CNSA, creating ressource centres for children and adults living with :
  - A double impairment of sensory functions : seeing and hearing, or of a sensory function associated to other impairments
  - Severe dysphasia
  - Complex disabilities linked to a severe, chronic and progressive diseases such as mitochondrial, metabolic or neurodegenerative disease, cerebral palsy resisting to treatment
- Following an INSERM international study, regional reports, then a national report(2013), the first definition of rare disabilities appears outdated. The need for a 2nd National Strategy is acknowledged.
- Rare disabilities are multiple disabilities with complex dependency needs, including communication problems. They require specific and rare expertise. Their prevalence is rare and not known.
- All existing resources at local, regional, national and European level must be identified and should work together. Coordination and good will are not enough. Integration of all available health and social services is needed

Developing integration of services a key challenge for CNSA!

- A process relying on all stakeholders :
  - national centres of reference and competence, resource centres
  - Regional and local institutions: Regional Health agencies, « conseils généraux » (« départements » elected bodies), education authorities, social security
  - Local actors: MDPH, mainstream and specialised schools, supporting social services, institutions, patient and families associations…
- Empower them, organise comprehensive evaluations and exchange of information and data
- Recruit interregional complex case managing teams to put together a specific answer to the individual needs of people with rare disabilities, publish and disseminate good practices… : 1 coordinator, secretariat and use of professionals part time.

Some successful pioneer experiences, based on good will

- Formalised links between special schools and groups homes and local psychiatric units, or emergency units. Local cooperation between services on difficult cases.

- *Case study: Mehdi, 14, with Prader Willi syndrome and severe behaviour problems, was expelled from a special school, spent 6 months in a psychiatry unit. Mother nightworker. Father unemployed, exhausted, ready to divorce, became abusive. After hours of meetings and trainings in the MDPH, Mehdi is now integrated in the week in another special school with individual support in the day, in a local psychiatric unit at night, and comes back home for the week end with a trained assistant. Everyone is happy and parents back together.*

2014 : creation of interegional complex case managing teams

- Three models of case managers already support people living with:
  - muscular dystrophies, funded by AFM-Téléthon
  - amyotrophic lateral sclerosis, funded by the association
  - Alzheimer : funded by the CNSA as a pilot, was considered costly, because of the number of people concerned.

- Recruited in 2014 by CNSA, case managing teams will identify resources, evaluate people with rare disabilities, empower families and help integrate:
  - Medical care: centre of expertise, ressource centres, medical specialists, local pediatricians or GP, local hospital, and paramedical care: nurses, physiotherapists, psychologists, dieteticians…
  - Social care: inclusion at local school and/or adapted schools, inclusion at work or in specialised workshops, support to carers, assistants at home, adapted housing, respite care…

  Linking with regional health agencies and local disability authorities (MDPH)

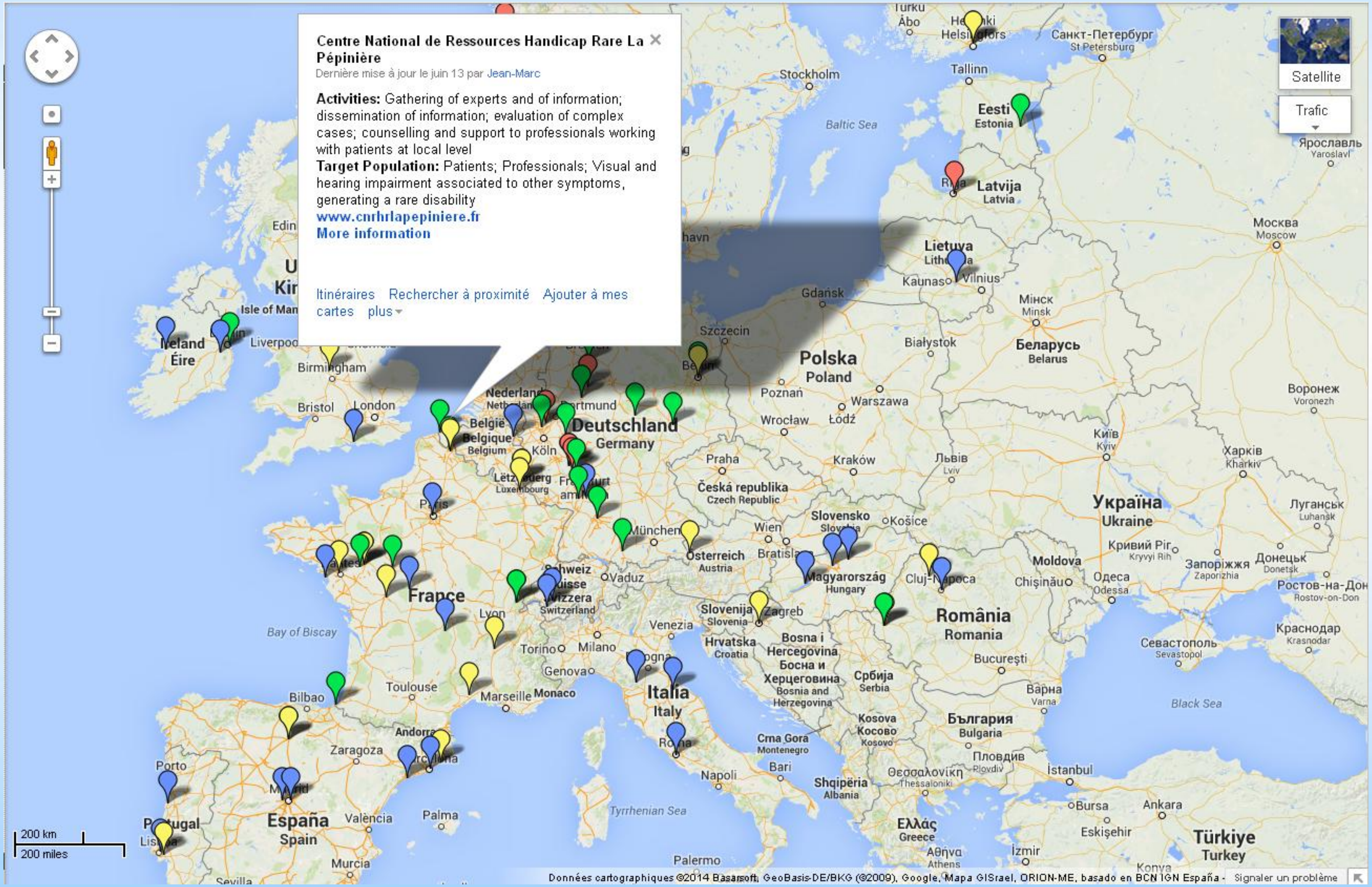
Equal access to care in different regions?

- A long road…
- CNSA issues annual reports underlining differences among regions.
- In 2013, the average number of applications of people living with disabilities in general, to the different MDPH, varied from 1,5 to 4.
- Each MDPH has a different governance, organisation, and dynamics.

Social services specialised for rare diseases and their funding

Données cartographiques ©2014 Basarsoft, GeoBasis-DE/BKG (©2009), Google, Mapa GISrael, ORION-ME, basado en BCN IGN España - Signaler un problème

Social services specialised for rare diseases and their funding



Centre National de Ressources Handicap Rare La Pépinière

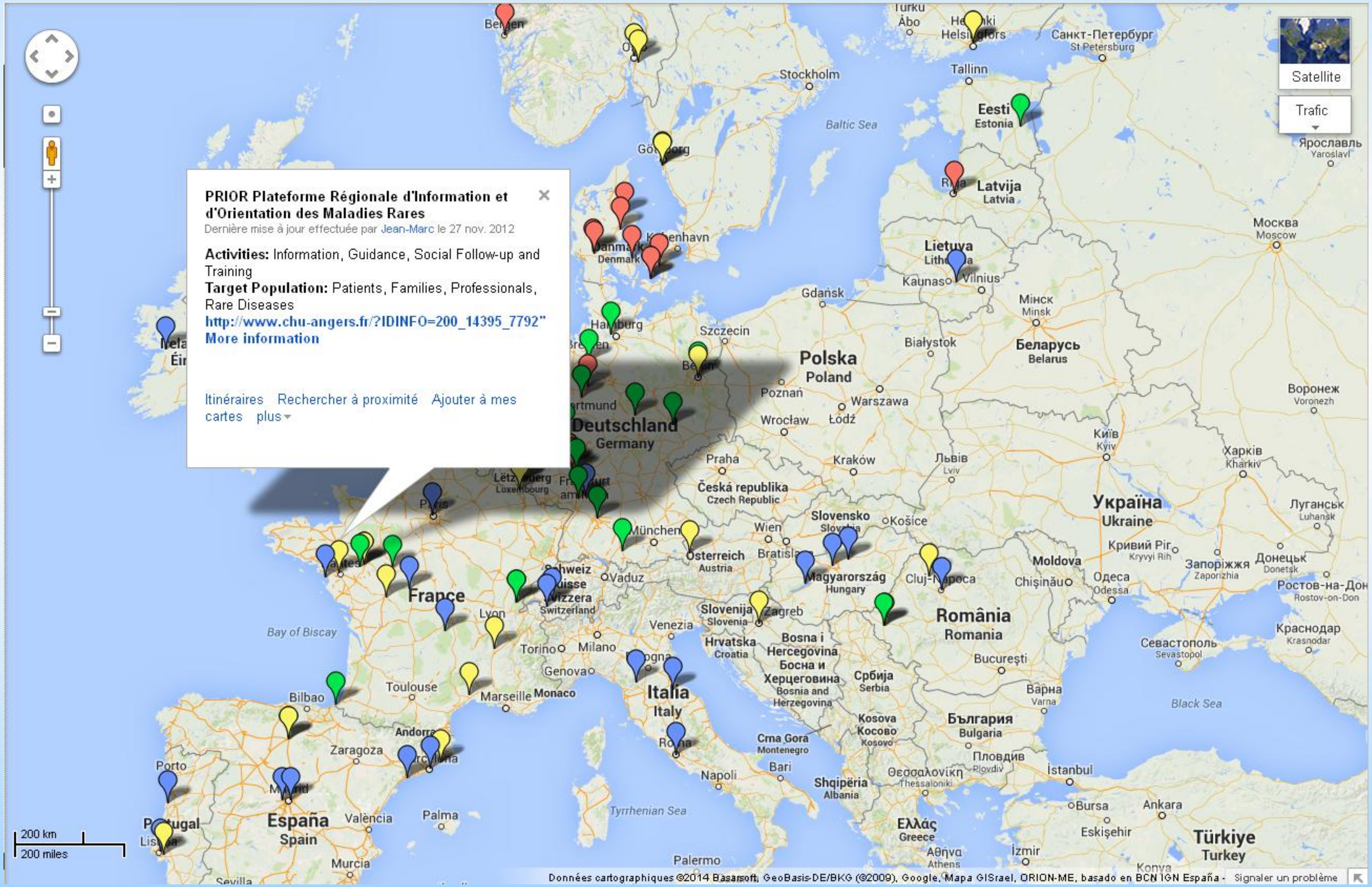
Dernière mise à jour le juin 13 par Jean-Marc

Activities: Gathering of experts and of information; dissemination of information; evaluation of complex cases; counselling and support to professionals working with patients at local level
Target Population: Patients; Professionals; Visual and hearing impairment associated to other symptoms, generating a rare disability
www.cnrhrlapepiniere.fr
More information

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Alliance maladies rares

Social services specialised for rare diseases and their funding



PRIOR Plateforme Régionale d'Information et d'Orientation des Maladies Rares

Dernière mise à jour effectuée par Jean-Marc le 27 nov. 2012

Activities: Information, Guidance, Social Follow-up and Training

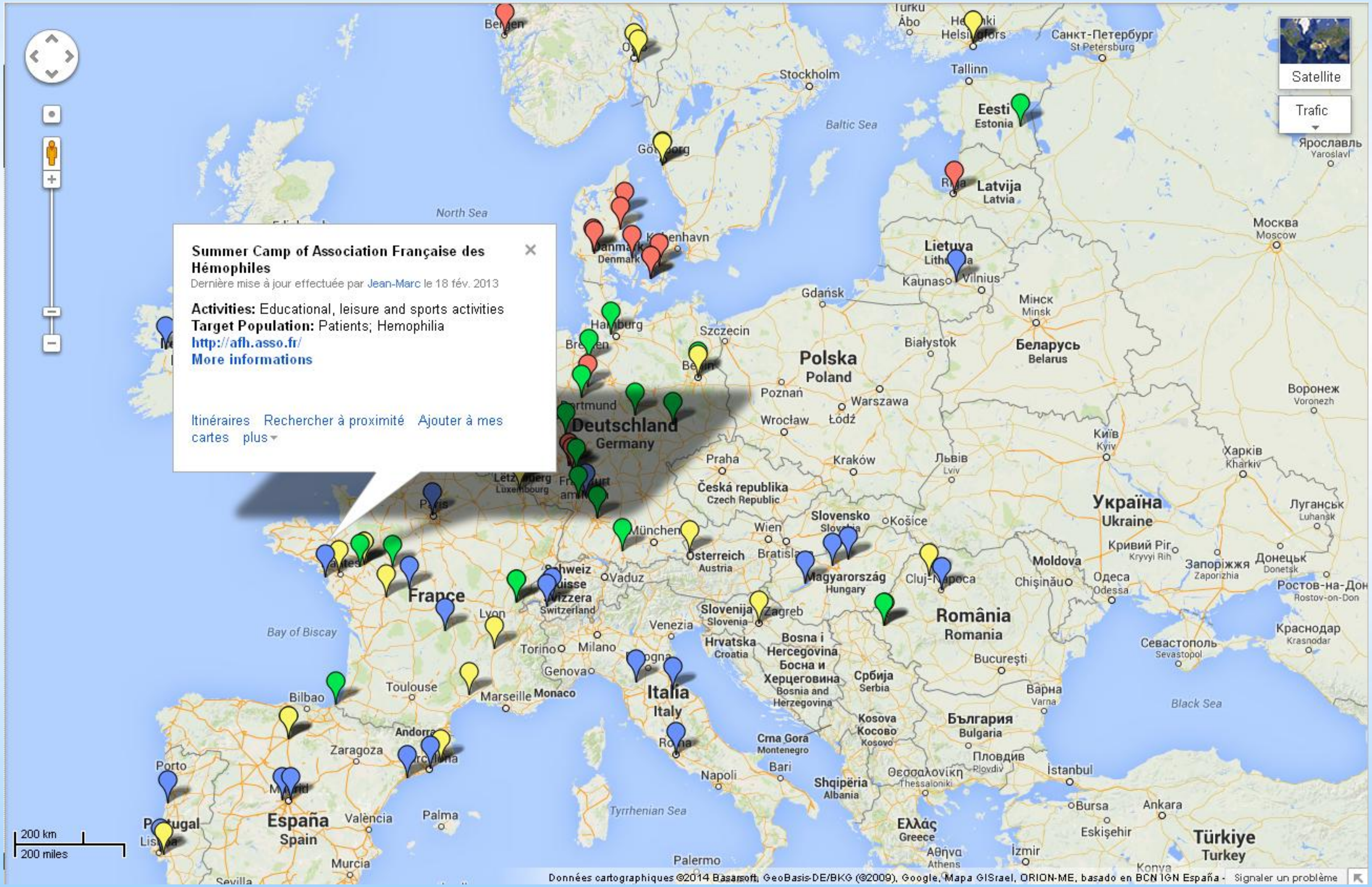
Target Population: Patients, Families, Professionals, Rare Diseases

http://www.chu-angers.fr/?IDINFO=200_14395_7792"

More information

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Social services specialised for rare diseases and their funding



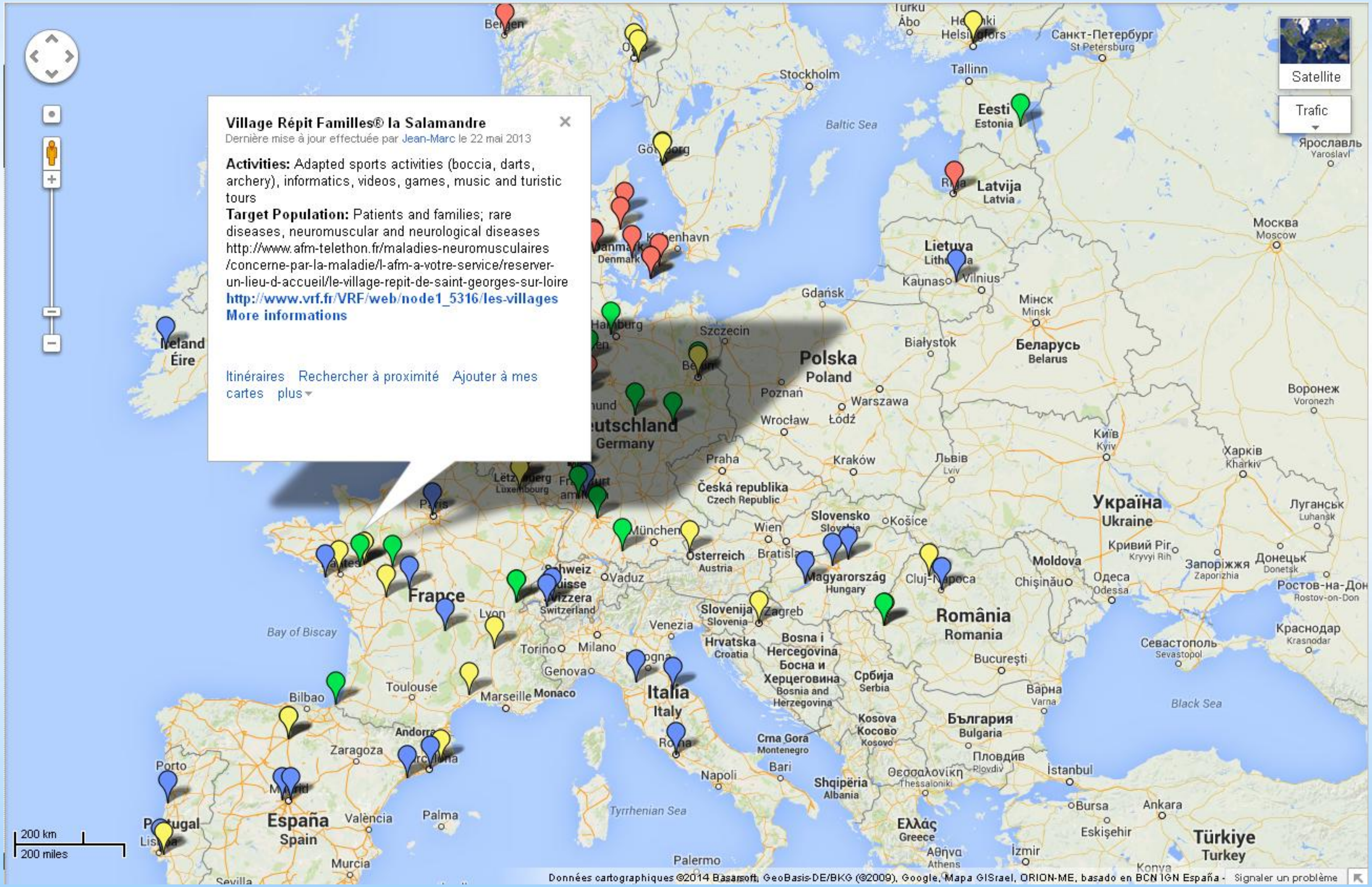
Summer Camp of Association Française des Hémophiles

Dernière mise à jour effectuée par Jean-Marc le 18 fév. 2013

Activities: Educational, leisure and sports activities
Target Population: Patients; Hemophilia
http://afh.asso.fr/
More informations

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Social services specialised for rare diseases and their funding



Village Répit Familles® la Salamandre

Dernière mise à jour effectuée par Jean-Marc le 22 mai 2013

Activities: Adapted sports activities (boccia, darts, archery), informatics, videos, games, music and turistic tours

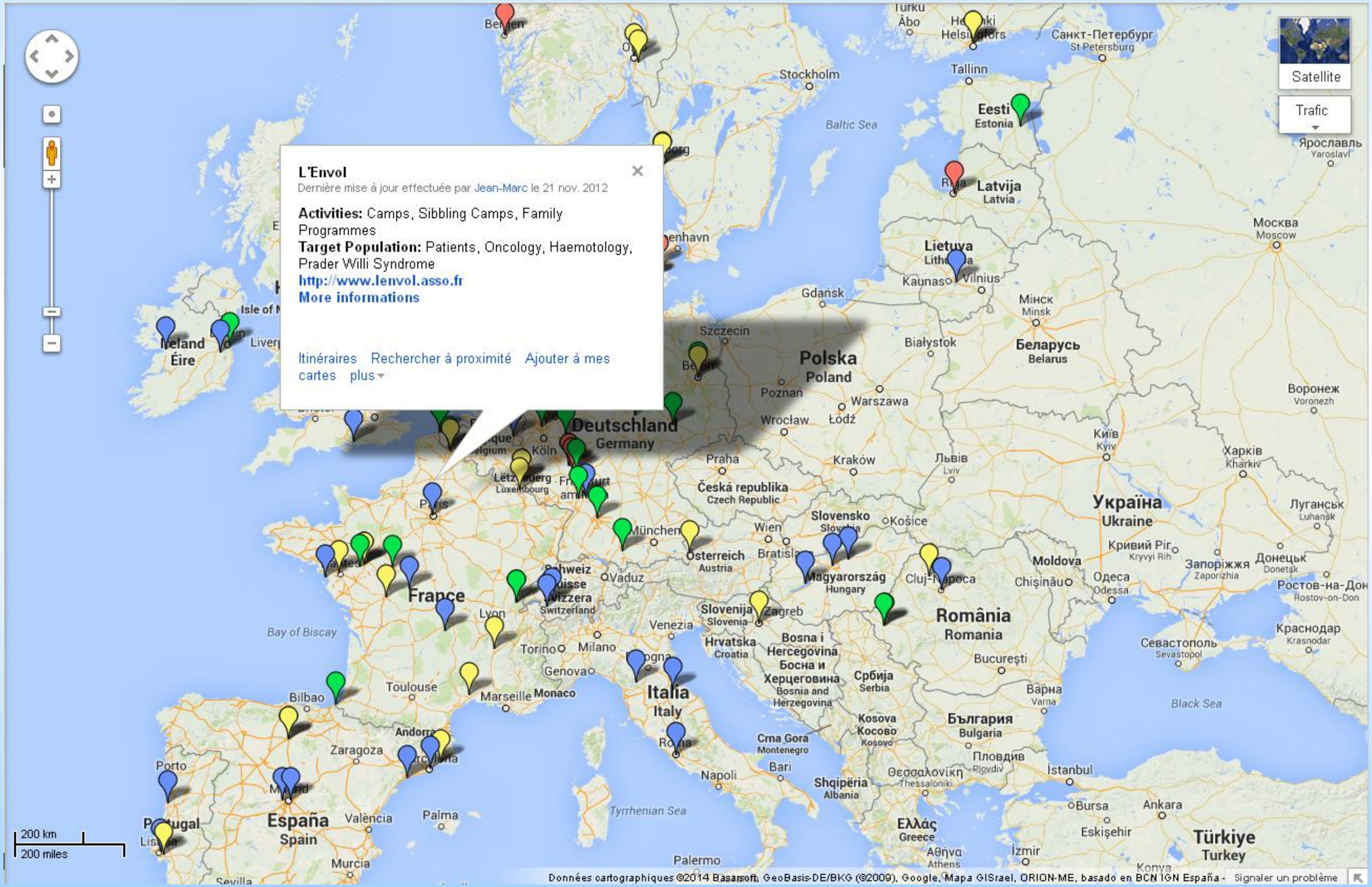
Target Population: Patients and families; rare diseases, neuromuscular and neurological diseases

http://www.afm-telethon.fr/maladies-neuromusculaires/concerne-par-la-maladie/l-afm-a-votre-service/reserver-un-lieu-d-accueil/le-village-repit-de-saint-georges-sur-loire

http://www.vrf.fr/VRF/web/node1_5316/les-villages

More informations

Social services specialised for rare diseases and their funding



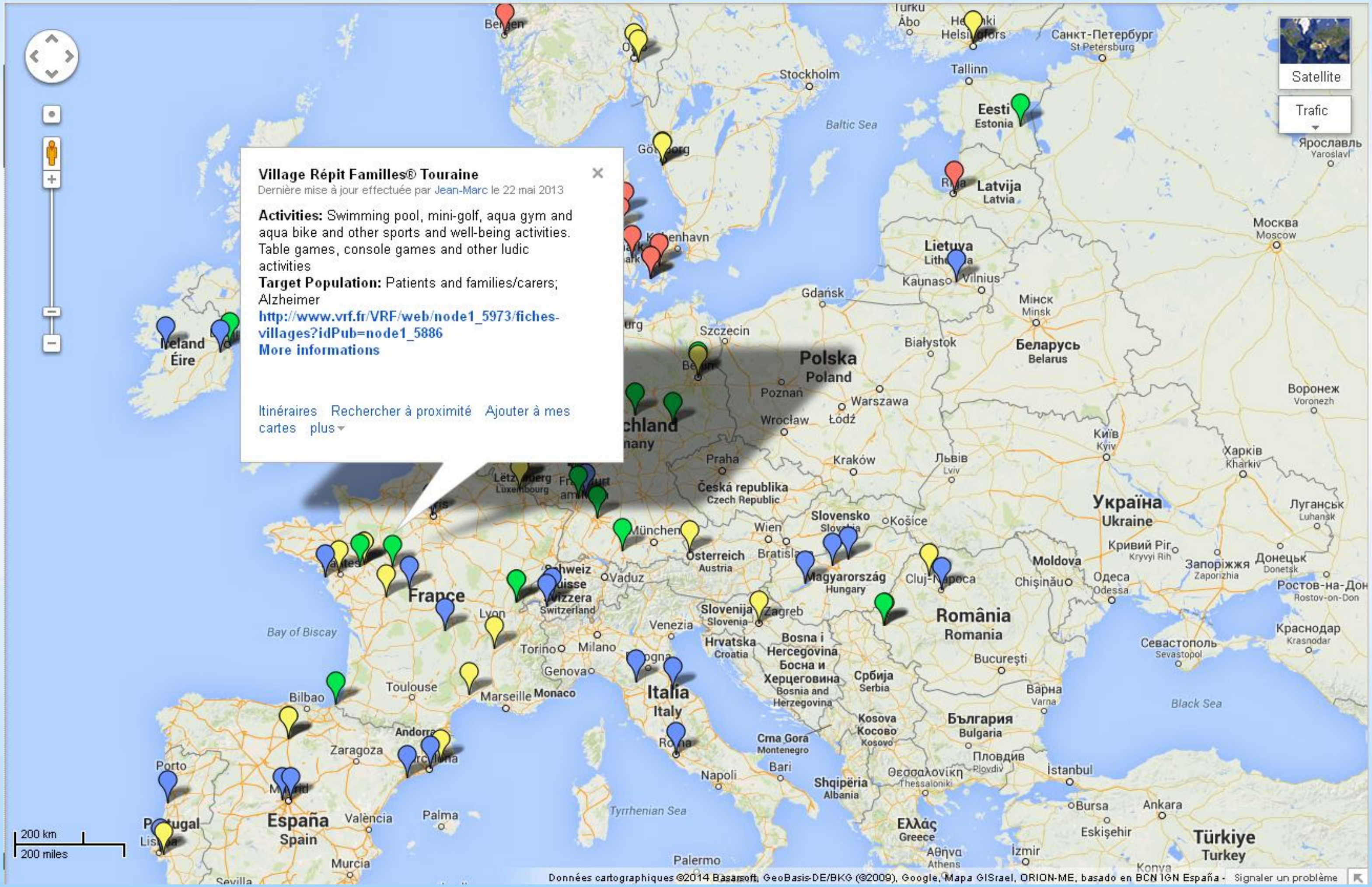
L'Envol

Dernière mise à jour effectuée par Jean-Marc le 21 nov. 2012

Activities: Camps, Sibbling Camps, Family Programmes
Target Population: Patients, Oncology, Haemotology, Prader Willi Syndrome
http://www.lenvol.asso.fr
More informations

Alliance maladies rares

Social services specialised for rare diseases and their funding



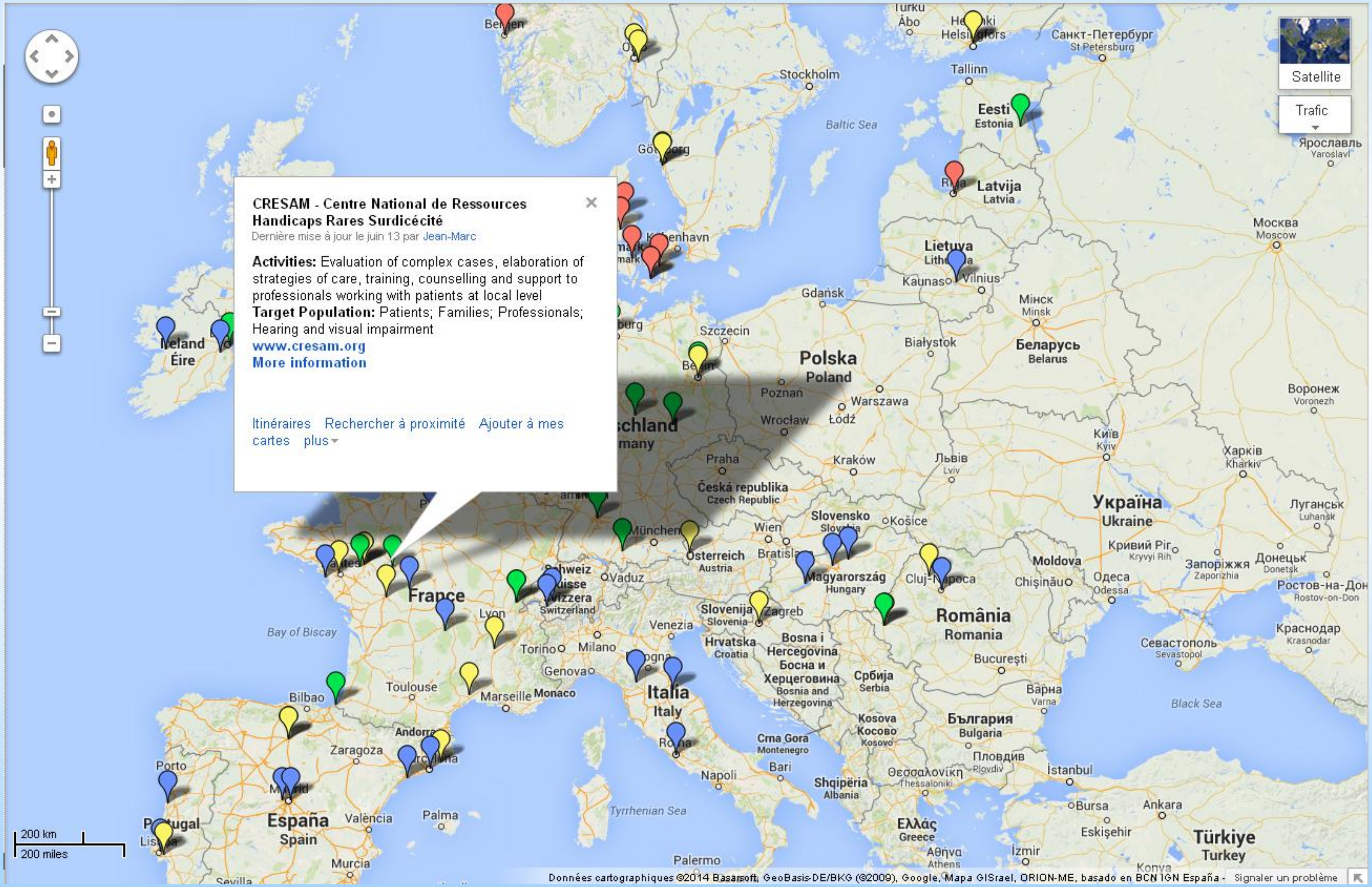
Village Répit Familles® Touraine
Dernière mise à jour effectuée par Jean-Marc le 22 mai 2013

Activities: Swimming pool, mini-golf, aqua gym and aqua bike and other sports and well-being activities. Table games, console games and other ludic activities
Target Population: Patients and families/carers; Alzheimer
http://www.vrf.fr/VRF/web/node1_5973/fiches-villages?idPub=node1_5886
More informations

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Données cartographiques ©2014 Basarsoft, GeoBasis-DE/BKG (©2009), Google, Mapa GISrael, ORION-ME, basado en BCN IGN España - Signaler un problème

Social services specialised for rare diseases and their funding

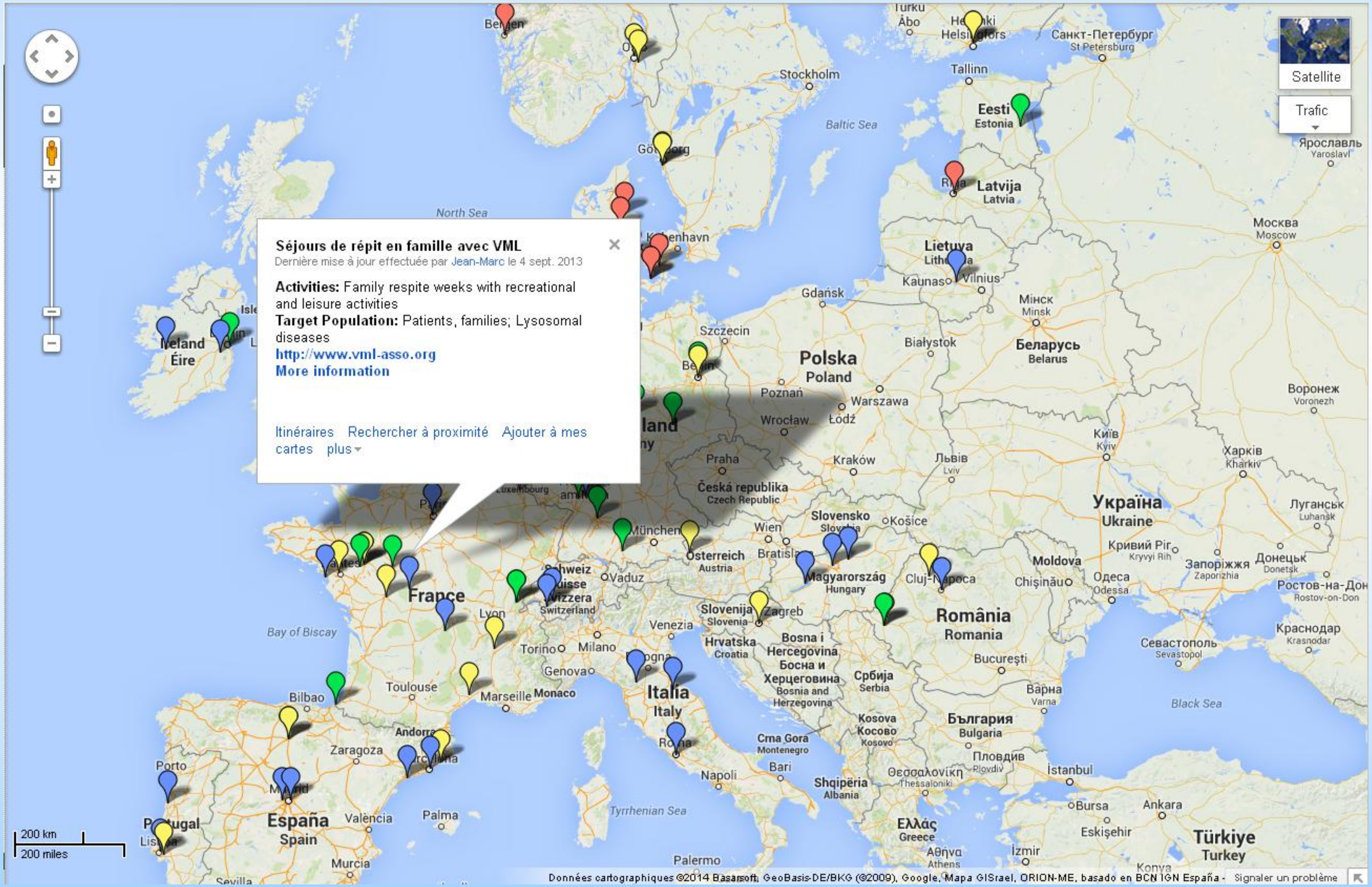


CRESAM - Centre National de Ressources Handicaps Rares Surdicécité
Dernière mise à jour le juin 13 par Jean-Marc

Activities: Evaluation of complex cases, elaboration of strategies of care, training, counselling and support to professionals working with patients at local level
Target Population: Patients; Families; Professionals; Hearing and visual impairment
www.cresam.org
More information

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Social services specialised for rare diseases and their funding



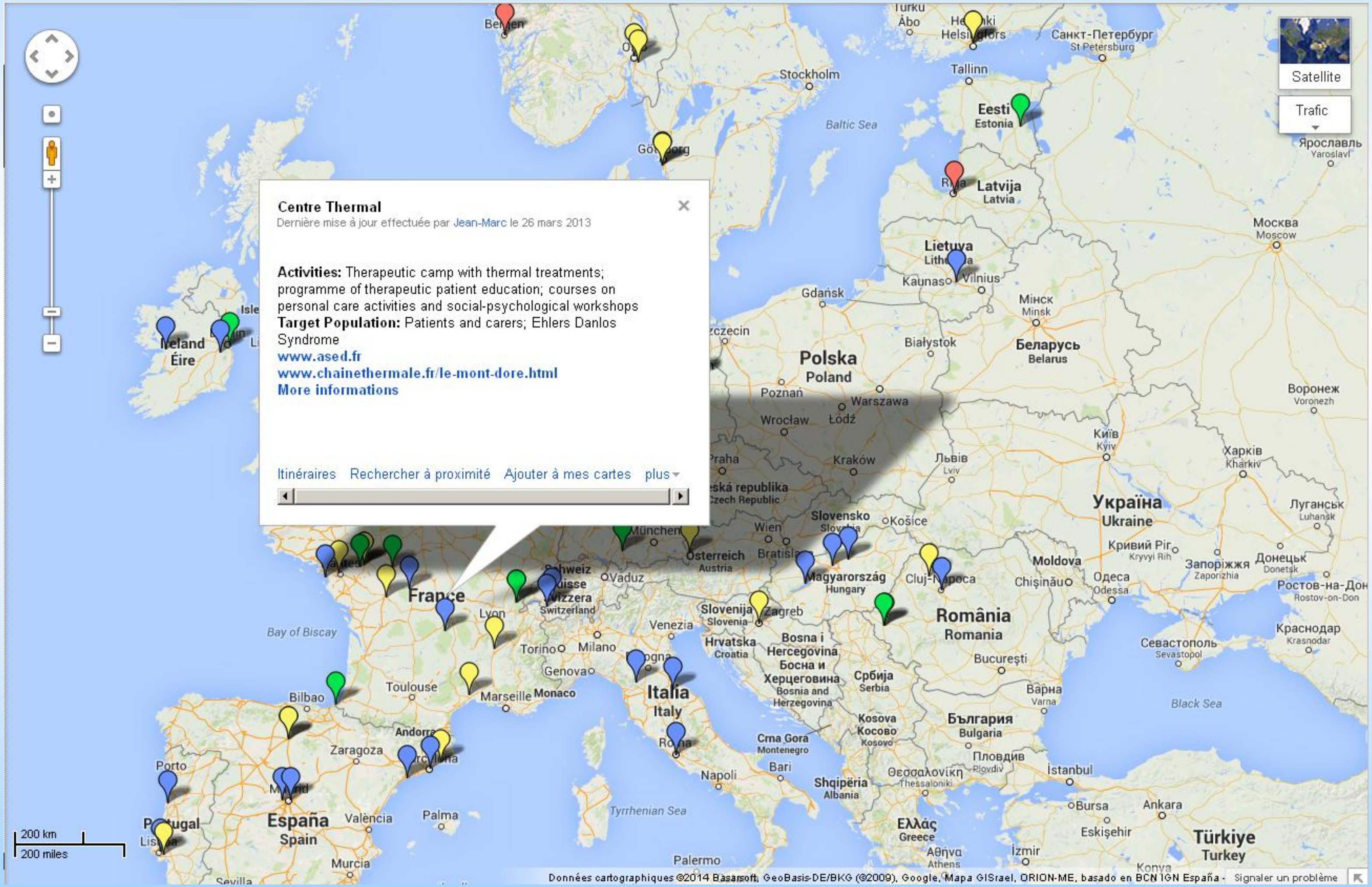
Séjours de répit en famille avec VML

Dernière mise à jour effectuée par Jean-Marc le 4 sept. 2013

Activities: Family respite weeks with recreational and leisure activities
Target Population: Patients, families; Lysosomal diseases
http://www.vml-asso.org
More information

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Social services specialised for rare diseases and their funding



Centre Thermal

Dernière mise à jour effectuée par Jean-Marc le 26 mars 2013

Activities: Therapeutic camp with thermal treatments; programme of therapeutic patient education; courses on personal care activities and social-psychological workshops

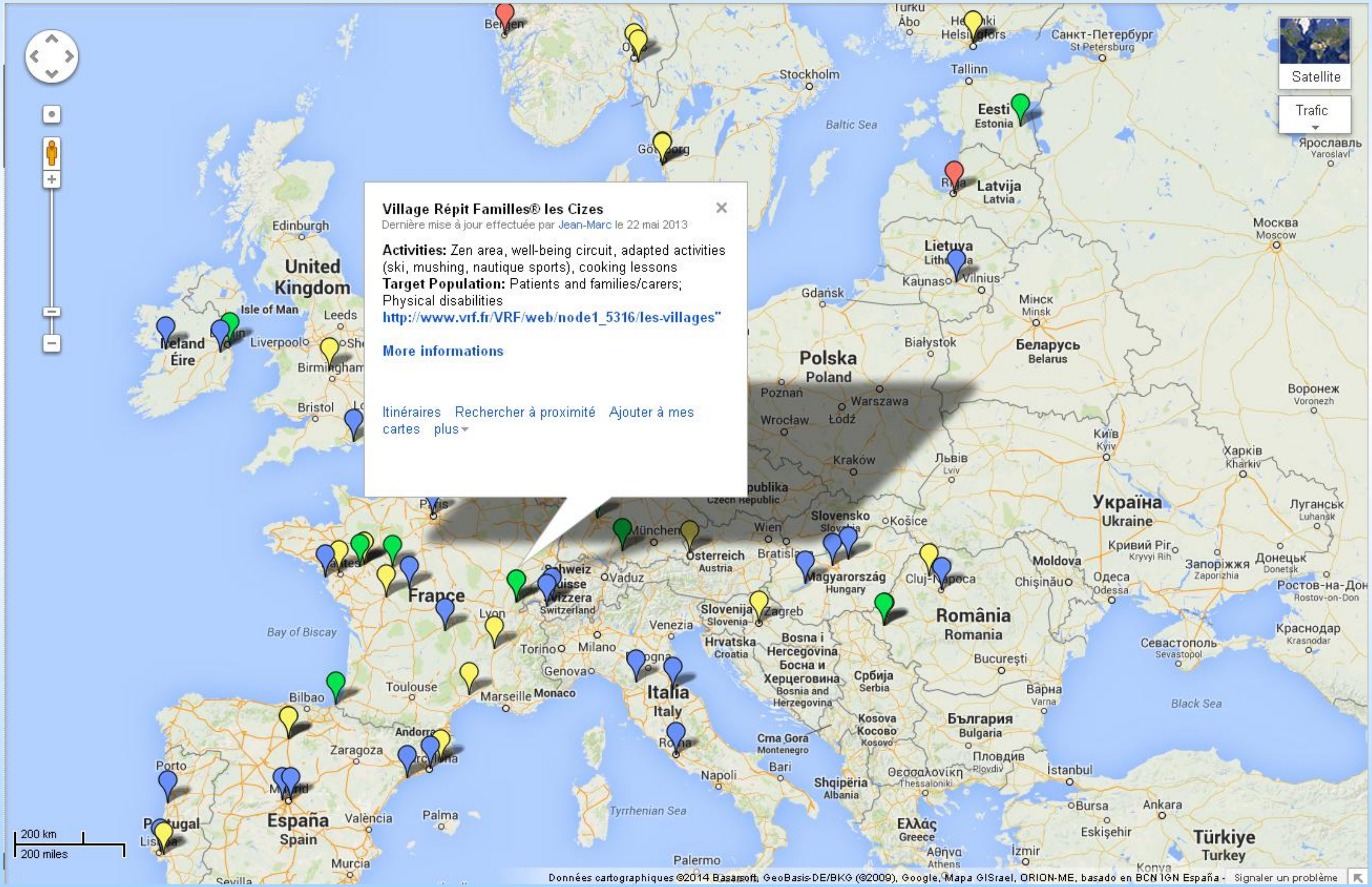
Target Population: Patients and carers; Ehlers Danlos Syndrome

www.ased.fr

www.chainethermale.fr/le-mont-dore.html

More informations

Social services specialised for rare diseases and their funding



Village Répit Familles® les Cizes

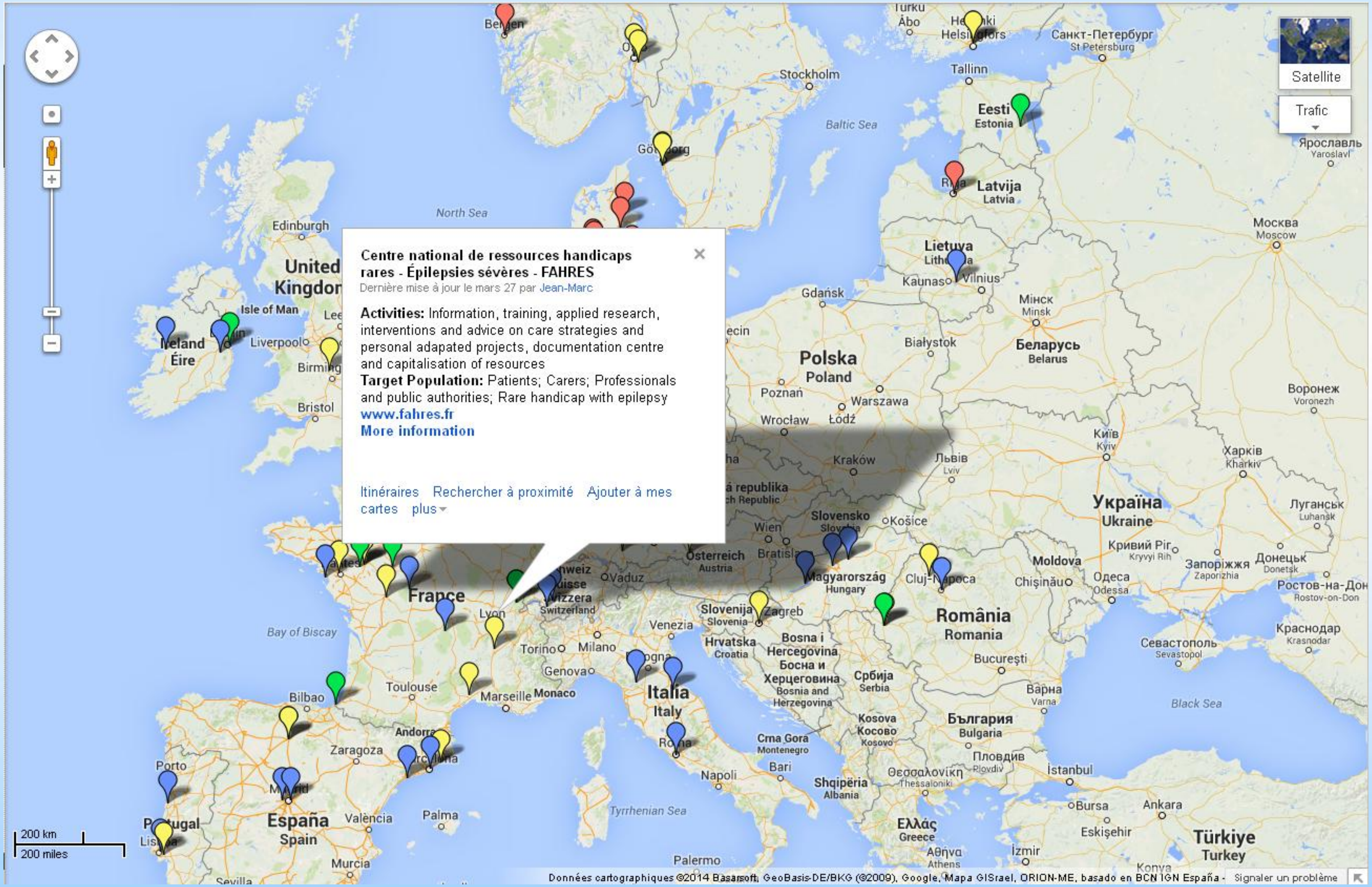
Dernière mise à jour effectuée par Jean-Marc le 22 mai 2013

Activities: Zen area, well-being circuit, adapted activities (ski, mushing, nautique sports), cooking lessons
Target Population: Patients and families/carers; Physical disabilities
http://www.vrf.fr/VRF/web/node1_5316/les-villages"

More informations

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Social services specialised for rare diseases and their funding



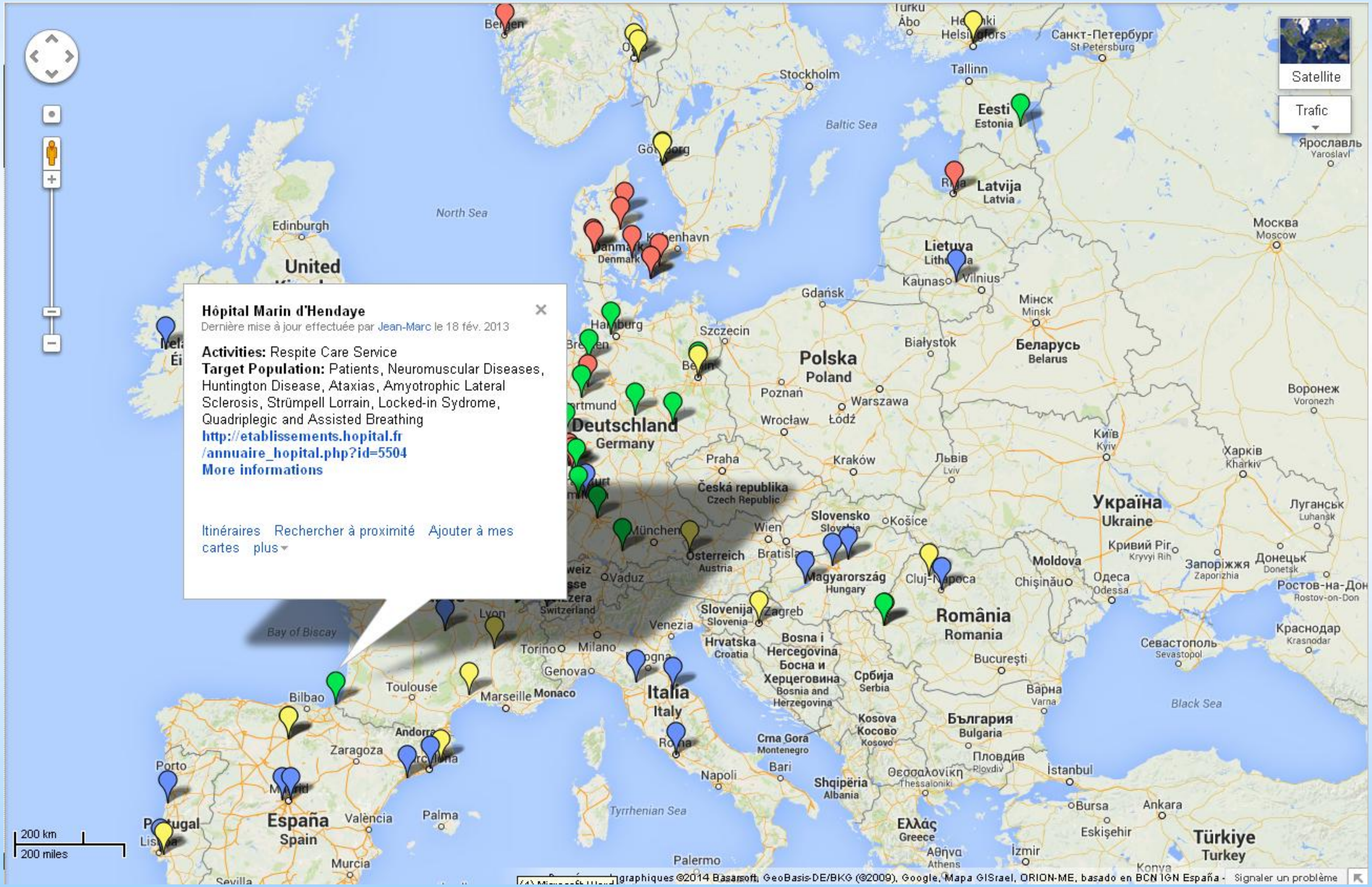
Centre national de ressources handicaps rares - Épilepsies sévères - FAHRES

Dernière mise à jour le mars 27 par Jean-Marc

Activities: Information, training, applied research, interventions and advice on care strategies and personal adapated projects, documentation centre and capitalisation of resources
Target Population: Patients; Carers; Professionals and public authorities; Rare handicap with epilepsy
www.fahres.fr
More information

Données cartographiques ©2014 Basarsoft, GeoBasis-DE/BKG (©2009), Google, Mapa GISrael, ORION-ME, basado en BCN IGN España - Signaler un problème

Social services specialised for rare diseases and their funding



Hôpital Marin d'Hendaye

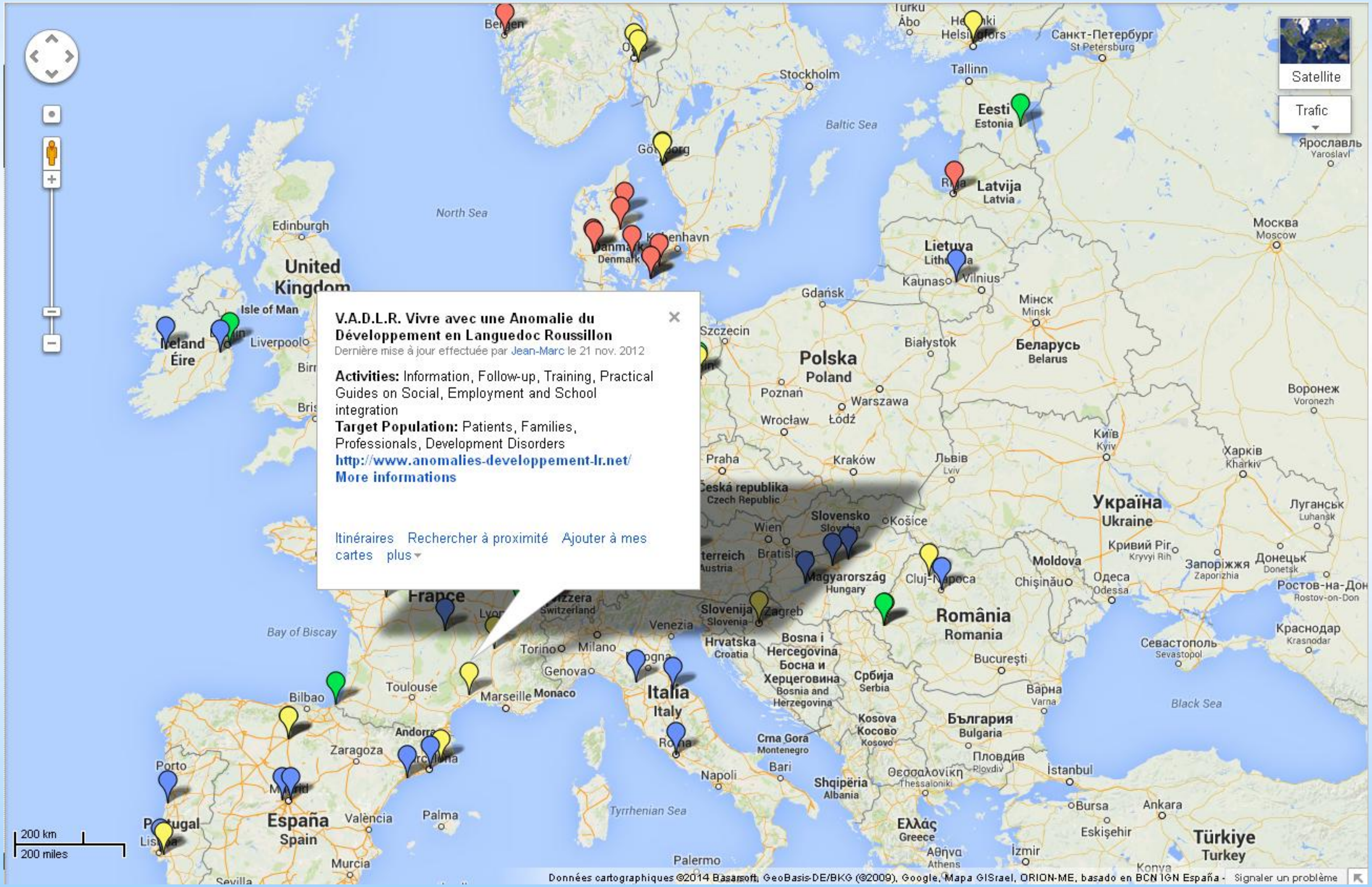
Dernière mise à jour effectuée par Jean-Marc le 18 fév. 2013

Activities: Respite Care Service
Target Population: Patients, Neuromuscular Diseases, Huntington Disease, Ataxias, Amyotrophic Lateral Sclerosis, Strümpell Lorrain, Locked-in Sydrome, Quadriplegic and Assisted Breathing
http://etablissements.hopital.fr/annuaire_hopital.php?id=5504
More informations

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

…graphiques ©2014 Basarsoft, GeoBasis-DE/BKG (©2009), Google, Mapa GISrael, ORION-ME, basado en BCN IGN España - Signaler un problème

Social services specialised for rare diseases and their funding



V.A.D.L.R. Vivre avec une Anomalie du Développement en Languedoc Roussillon
Dernière mise à jour effectuée par Jean-Marc le 21 nov. 2012

Activities: Information, Follow-up, Training, Practical Guides on Social, Employment and School integration
Target Population: Patients, Families, Professionals, Development Disorders
http://www.anomalies-developpement-lr.net/
More informations

Itinéraires Rechercher à proximité Ajouter à mes cartes plus

Key issues to share good practices

- Evaluation
- Better use of all expertises: clinicians, paramedics, social professionals, patients, families…
- Coordination/integration of services